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ABSTRACT

This fact sheet uses a question-and-answer format to provide basic information about changes in vision for older adults and what kind of services are needed particularly adults with developmental disabilities. Questions address the following topics: the importance of eye exams for adults with developmental disabilities; the need for eye exams even if the individual does not read or do other close work; recommended frequency of eye exams; types of eye care specialists; the exam; visual acuity; legal blindness; symptoms of a vision problem in an adult with developmental disabilities; information to provide the eye-care specialist; vision changes that are possibly more common in people with developmental disabilities; typical changes in vision as people age; common eye diseases of older people; diseases that can cause vision loss or blindness; how vision loss affects the adult with developmental disabilities; ways to make the best of existing vision capabilities; and other vision professionals who may provide additional ideas about making the most of remaining vision. A list of suggested print and organizational resources is attached. (DB)

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ED 417 516

Aging With Mental Retardation

Aging With Developmental Disabilities: Changes in Vision

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Older adults with developmental disabilities are living longer than ever before. Most have the ability to live happy, productive lives in their communities. Like other older adults, it is critical for adults with developmental disabilities to receive regular vision screening to identify age-related changes and eye diseases that can have an impact on their independence, safety, and quality of life.

This fact sheet has been designed for family members and service providers who will be helping adults with developmental disabilities obtain the care they need to age successfully. It will provide basic information about changes in vision for older adults and how to help older adults with developmental disabilities have the best vision possible.

How important are eye exams for adults with developmental disabilities?

As we age, our eyesight changes. Most of these changes are normal, age-related changes that do not present a serious threat to one's well-being. However, as we live longer, more and more people will experience a significant impairment of their vision that will hinder their ability to function independently on a daily basis. It is very important that older adults see an eye care specialist on a regular basis since many causes of vision impairment are treatable and vision loss can often be prevented.

Also, a change in a person's behavior resulting from an undiagnosed vision problem could be mistaken for another serious problem, e.g. Alzheimer's Disease. Accurate diagnosis and treatment are critical for the person's well-being as he ages.

If an adult with a developmental disability does not read or do any close work using her eyes, is an eye exam still necessary?

Yes, an eye exam will detect if the individual has an eye disease. Many treatable causes of vision loss are never apparent to someone looking from the outside, without the aid of special instruments. If left untreated, eye diseases can cause blindness or severe impairment which can interfere with an individual's safety in walking, the ability to understand what is expected of her, or the enjoyment of her surroundings.

How often should eye exams be scheduled?

Eye exams should be done every one to two years, or more often upon the instructions of the eye care specialist. For adults with developmental disabilities who may not be able to identify a change in

Authors' note: This information is pertinent to all people with developmental disabilities.

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vision and communicate this to family and staff, it is vitally important that routine eye health exams are provided on a regular basis. There is not a specific age at which someone should begin to have routine eye exams on a yearly basis; however, women over age 35 and men over 40 are at a higher risk for age-associated eye diseases. An eye specialist can best determine how frequently exams need to be scheduled for each individual.

With what type of eye care specialist should an appointment be scheduled?

An appointment can be scheduled with either of the eye care specialists listed below.

Ophthalmologists - These specialists are doctors of medicine (M.D.) or osteopathy (D.O.). They are licensed to practice medicine and surgery and can prescribe glasses, contact lenses, and medications.

Optometrists - These specialists are doctors of optometry (O.D.). They are licensed to practice in select areas of vision care which varies from state to state. They can evaluate people for visual problems and prescribe glasses and contact lenses. In most states they may diagnose and treat eye diseases.

Some eye care providers may not be comfortable or skilled in working with people with developmental disabilities. Some specialists may gain comfort and experience over time; the involvement of a family member or other care provider who knows the person with disabilities can help this process. At other times, it will be to everyone's benefit to identify a different specialist who is interested in working with adults with developmental disabilities.

What is done during an eye exam?

A complete eye exam will assess two major things:

- how the person can see, i.e. visual acuity and
- if he has any eye diseases.

The specialist will make recommendations such as glasses, magnifying lenses, medication or surgery.

What is visual acuity?

Visual acuity means the ability of the eyes to see and distinguish small details. This is measured on an eye chart and is usually recorded in terms such as "twenty-twenty" or twenty-thirty." When written it looks like this: 20/20 or 20/30. The first number indicates the distance (in feet or meters) at which the vision was tested. The second number indicates the size of the symbol that was seen. 20/20 is not perfect vision; rather, it is considered to be normal vision.

What is legal blindness?

People who are legally blind may not be totally blind; about 80% have some useable vision. Most people with vision problems such as near-sightedness, far-sightedness, or astigmatism can have 20/20 vision when wearing their glasses or contact lenses. People who are legally blind can see no better than 20/200 even with their glasses on. A person can also be legally blind even if she sees clearly but the area that can be seen at one time (field of view) is reduced to less than 20 degrees. This is sometimes called "tunnel vision."

How will I know if an adult with a developmental disability might be having a problem with his vision?

1. **Ask** the person if he has any trouble seeing, has any pain, or other unusual symptoms. Ask if he can see about the same when either eye is covered.

2. **Observe** him for changes in behavior and function. The following changes in behavior might indicate a change in vision: rubbing the eye; squinting; shutting or covering one eye; tilting or thrusting the head. Changes in function which might indicate a vision problem include: stumbling; hesitancy on steps or curbs; holding reading material (or other fine work) closer than usual; refusing to engage in activities which he previously enjoyed; sitting closer to the television than in the past. If these or similar symptoms are noticed, an appointment with an eye care specialist should be scheduled.

3. **Expect** changes as the person ages.

What information will be helpful to an eye care specialist?

It is a good idea to gather the following information and take it to the appointment. This will help the specialist provide a better assessment for the adult with a developmental disability and to make recommendations that are specific to her daily life.

- What physical or mental illnesses/conditions does the person have?
- What medication does she take for these conditions?
- When was the last eye exam?
- Who did this exam?
- Was an eye disease diagnosed at that exam?
- Were corrective lenses, medicines, or other treatments recommended at that exam? If so, were they purchased and are they being used?
- Was a follow-up appointment recommended? If so, was it made and kept?
- What signs of possible vision changes have you observed?
- What kinds of activities does the adult with a developmental disability do in her daily life, e.g. what does she do at work? Does she read or do other activities using near vision? Or does she utilize her vision primarily for safety (e.g. walking).
- Has there been a change in her abilities or interests, e.g. does she no longer do activities that were enjoyable in the past, like reading, or needlework; is she having difficulty with work tasks that she used to know well?

Do people with developmental disabilities experience vision changes that are different from those that the general population experiences?

There has been little research on the changing health of the eyes of older adults with developmental disabilities. This may be due, in part, to the fact that the presence of increasing numbers of older people with developmental disabilities is a recent phenomenon.

Findings from the scant research that have been conducted have indicated that there are many adults with developmental disabilities who have strabismus (eye muscle imbalances) and large refractive errors (nearsightedness, farsightedness, and astigmatism). The prevalence of cataracts and keratoconus (a disease marked by the swelling and scarring of the cornea) have varied by study, and have been reported as high as 50% and 30%, respectively.

It is known that adults with Down syndrome are at greater than normal risk for eye disorders, and that age-related disorders seem to occur for them at an earlier age than for other older adults.

What are typical changes in vision as people age?

As we age, all of our senses change, including vision. The average person will probably experience most of the following as he gets older:

Can't see as clearly as before (loss of visual acuity). As the lens of the eye ages, it becomes denser and cloudier, cutting down on the amount of light that passes through to the retina. In turn, the retina (the inside lining of the eye that receives the image) is less capable of doing this job and may send a picture to the brain that is less sharp or clear than in the past.

Difficulty seeing objects up close (loss of accommodation) - a condition called "presbyopia." As the eye ages, the lens becomes more rigid and loses its ability to focus on objects that are held close, e.g. a newspaper. For most people, this is usually taken care of with the use of reading glasses or bifocals.

Need for more light (decrease in light transmission). Because the pupil of the eye is less able to expand and let light in, and because the lens has become more dense, the older eye requires as much as three times more light.

Changes in color perception. The fibers of the lens take on a yellow hue which may cause the eye to be better able to distinguish red/orange/yellow than blue/green.

More difficulty seeing in the dark (decrease in dark adaptation). The pupil becomes smaller with age due to changes (atrophy and rigidity) in the iris. Thus, it is more difficult to see in the dark than when we were younger.

Less able to adapt to glare. Resistance to glare is 2.5 times greater at age 20 than at age 65. This is due to changes in the pupil and the lens.

Loss of side vision (decreased visual field). As the retina changes, the eye may be only half as capable of detecting peripheral (side) motion as it did when people were 20 years old.

What eye diseases are more likely to occur as people age?

In addition to the age-related vision changes that occur for most older adults, some people will experience eye diseases. Two common diseases that can be bothersome and might lead to vision impairment are:

Dry eyes. Someone may complain of scratchy, irritated eyes. This can be due to reduced or irregular tear production that keeps the surface of the eye (cornea) lubricated. Sometimes, too many tears are produced at the same time causing them to spill over the eyelids. After diagnosis by an eye care provider, this is usually treated with artificial tears or ointments.

Blepharitis. Red, itchy eyelids are usually a sign of this condition. An eye care specialist may recommend medication or special cleansing of the eyelids to treat this condition. Rubbing of the eyes to relieve itching may lead to the development of keratoconus, a serious disease of the cornea. Blepharitis is a common occurrence in people with Down syndrome.

What are the most frequent diseases that can cause vision loss or blindness?

Other eye diseases associated with aging can be serious threats to a person's vision. Often, these

are painless and gradual in onset. Only an eye care provider can properly diagnose them. These eye diseases include:

Age-Related Macular Degeneration (ARMD). This disease causes damage to the part of the eye that is responsible for detail vision (the macula). While the person with ARMD always retains her side (peripheral) vision, the central blind spot caused by this disease can cause an inability to read, recognize faces, or do "close work."

Cataracts. When the clear lens inside the eye becomes cloudy or develops opacities, it is called a cataract. Cataracts can greatly impair vision; however, they do not usually damage the eyes. Most cataracts can be successfully removed through surgery.

Diabetic Retinopathy. If a person has long-term diabetes, damage can occur to the retina (the nerve layer inside the eye). Vision loss may occur in varying degrees and total blindness may result.

Glaucoma. This disease is often called "the sneak thief of sight." It can cause a gradual loss of side (peripheral) vision and may lead to total blindness. Early detection and treatment are the only ways to save the most vision.

Keratoconus. Keratoconus is a disease of the cornea (the surface of the eye). It is more common in persons with Down syndrome. It can occur at any age. It may be associated with excessive rubbing of the eyes (see blepharitis and dry eyes, above).

How will vision loss affect the adult with developmental disabilities?

The impact of vision loss on an individual's ability to perform activities of daily living (ADLs) can vary greatly from one person to another. Each person's unique situation should be addressed, rather than making a blanket statement based on the diagnosis of a disease or symptoms of age-related change. In general, however, vision loss can be placed into three categories.

Loss of central vision. Most often this type of loss is due to a disease, like macular degeneration. This means that there will be a loss of visual acuity or clarity. A central blind spot (scotoma) may cause the individual to not see details, or to miss seeing small objects which are close to him or large objects which are in the distance. His remaining side (peripheral) vision usually will allow him to move about safely in a familiar environment.

Loss of side (peripheral) vision. Loss of side vision is sometimes called "tunnel" vision. This is most often caused by glaucoma or a disease called retinitis pigmentosa (RP). While a person with this type of visual impairment may be able to see details in objects or read print, he may have difficulty moving about in the environment—especially one that is open or unfamiliar.

Diffuse blurriness across the entire field of vision. Typical causes of this type of impairment are cataracts, diabetic retinopathy, or keratoconus. These conditions may cause the vision to fluctuate based on the amount of light and the direction from which it is coming.

What can be done to make the best of the vision that someone has?

It is not possible to address every type of problem that a person with a visual impairment might encounter. However, in addition to using glasses or other aids recommended by the specialist, the following are some ways in which she can be helped to get the most out of her remaining vision.

1. **Question the eye care specialist.** Learn from the eye care specialist what type of vision loss the individual is experiencing, e.g. blurriness, or central vision loss etc. so you understand what the individual is experiencing every day.

2. **Change expectations.** Based on what you learn from the specialist, alert other family members and staff about what the individual is experiencing. Change expectations of the person that are no longer reasonable because of her vision loss.

3. **Modify the environment.** Enlist the help of other family members or staff, to modify the home or environment to accommodate the vision loss to the extent possible.

4. **Provide additional lighting.** Many times, near vision can be enhanced by providing increased illumination. Task lighting, the use of individual lights for specific tasks, can be very helpful. The light should have a gooseneck or flexible arm so that it can be brought close to the object being viewed. It should also have an adjustable cone or shield around the bulb so that the light can be directed onto the target item and away from the eyes. An insulated cone or shield will reduce the risk of burns to the hands.

5. **Use contrast.** Increasing contrast between the object to be viewed and the background or foreground can be helpful. For example, placing a light colored dinner plate on a dark colored place mat can help with general orientation to objects at the table. Try not to use blue and green together unless one color is significantly lighter than the other.

6. **Use magnification.** Making objects large or closer, or causing them to appear larger or closer, can often help the person with a visual impairment to gain more visual information and enhance the ability to see. Magnification may be achieved by using various types of lenses, by enlarging the object (e.g., large print) or by decreasing the distance between the viewer and the object. For example, it is often easier to see the TV more clearly when sitting closer to it.

7. **Reduce glare.** Try to minimize shiny, highly polished surfaces in the home or work place, e.g., close curtains to reduce glare on the kitchen floor and counters.

8. **Engage in daytime activities; provide additional support in the dark.** Recognize that the person may be more uncomfortable and need more support when it is dark. If possible, offer her a choice of going to an activity during the day or during the night (e.g. a matinee versus an evening performance).

9. **Allow time for adjustment to changes in lighting.** Be aware that it may be difficult to adjust to sudden changes between light and dark, e.g. when the person walks into a dark building after being in the sunshine. Allow time for the person's eyes to adjust.

10. **Protect the "good" eye.** If an individual has significantly better vision in one eye than in the other, she should be encouraged to wear "protective" glasses with lenses made of polycarbonate. This will help protect the "good" eye from injury or trauma. These should be worn even if they do not improve eyesight.

11. **Organize.** Help the person organize items that she uses frequently, e.g., in the closet, hang dress shirts in one area, t-shirts in another, etc.

12. **Be consistent.** It may be helpful to keep the environment at home and at work unchanged to the extent possible, e.g., minimize changes in furniture placement, orient and remind the person when changes are made.

Who can help provide additional ideas to help make the most of remaining vision?

The following professionals can usually be located through state or private agencies for the blind (see list of agencies below).

Low Vision Therapist - This is a person with specialized training who works in a team with the ophthalmologist or optometrist. He works with people who have impaired vision to help them learn to use special skills and aids to make the best use of their remaining vision.

Orientation and Mobility Specialist - This instructor teaches persons who are blind or visually impaired how to travel as safely and independently as possible. This may involve the use of a sighted person as a guide or the use of a white cane.

Rehabilitation Teacher of the Blind - This is a professional who is trained to teach activities of daily living (ADLs) to persons who are blind or visually impaired.

Where can a person get additional information and assistance regarding vision problems?

AGENCIES

The public agency in your state that serves adults who are blind and visually impaired, e.g., the Commission for the Blind.

Larger communities may have private agencies that provide the same or similar services as do public agencies. You can locate these agencies through the yellow pages in the telephone book.

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
(212) 502-7600 (800) 232-5463

Lighthouse National Center for Vision and Aging
111 East 59th Street
New York, NY 10022
(212) 821-9200 (800) 334-5497
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PUBLICATIONS

Coping with Low Vision
by Marshall Flax, Don Golembiewski & Bette McCaulley
This self-help guide and resource manual shows how a person can take care of him or herself with dignity, get around safely, and who can help find extra assistance in the person's community. 1993. 199pp. Singular Publishing Group, Inc., San Diego.

Making Life More Livable
by Irving R. Dickman
This book shows how simple adaptations in the home and environment can make a big difference in the lives of older persons who are blind or visually impaired. 1983. 96pp. AFB Press. Photos, illustrations, appendix.

Vision: Concerns for Older Persons Who Have a Developmental Disability
This is a six-page pamphlet in large print from the Lighthouse National Center for Vision and Aging.

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Aitchison, C., Easty, D.L., & Jancar, J. (1990). Eye abnormalities in the mentally handicapped. Journal of Mental Deficiency Research, 34, 41-48.

Flax, M.E., Golembiewski, D., & McCaulley, B. (1993). Coping with low vision. San Diego, CA: Singular Publishing Group.

France, T.D. (1992). Ocular disorders in Down syndrome. In I. T. Lott & E.E. McCoy (Eds.), Down syndrome: Advances in medical care (pp. 147-154). New York, NY: Wiley-Liss, Inc.

Hestnes, A., Sand, T., & Fostad, K. (1991). Ocular findings in Down's syndrome. Journal of Mental Deficiency Research, 35, 194-203.

Kallman, H. & Vernon, M.S. (1987). The aging eye. Postgraduate Medicine, 81:2.

Lighthouse National Center for Vision and Aging. Vision: Concerns for older persons who have a developmental disability.

Sacks, J.G., Goren, M.B., Burke, M.J. & White, S.S. (1991). Ophthalmologic screening of adults with mental retardation. American Journal on Mental Retardation, 95:5, 571-574.

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Important Information

Take this vision information sheet to the next eye exam. The questions below may help you remember what information to obtain **from** the eye care specialist at the end of the examination. Take along a pad of paper and a pencil or pen to make notes. Also, offer to let the eye care specialist make a copy of this informaton sheet for other patients who could benefit from this material. (Remember also to take information **to** the eye care specialist. Refer to the section titled, "**What information will be helpful to an eye care specialist?**" on page 3).

1. How well can the person see?
2. If she has low vision, what is she able to see and not able to see?
3. If she has low vision, can it be corrected?
4. If it cannot be corrected, what suggestions do you have to make the most out of her remaining vision?
5. Is there an eye disease present? If yes, what is it?
6. What was the cause of the disease?
7. Will it get better, get worse or stay the same?
8. Will anything improve or worsen the condition, e.g. medications, diet, surgery, use of the eyes, glasses?
9. What follow-up care is needed and how often?
10. Are relatives at risk for developing this disease?
11. Are there any rehabilitation services or agencies that could be helpful?

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